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AUTHOR	Tucker, Cindy L.; Hansen, James C.; Zevon, Michael A.
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ABSTRACT

Childhood cancer and its treatment have been identified as significant stressors for individuals and families. The impact of this experience on healthy siblings has not been clearly determined. This study was designed to assess siblings regarding their adjustment and their perceptions of their families following a sick sibling's treatment. Standardized measures were used to facilitate comparisons. Siblings of children who survived cancer (n=25) were compared with siblings of children who died of cancer (n=24) so as to understand the complexities of the experience relative to treatment outcome. Subjects were 49 siblings, ranging in age from 10 to 20 years, and their parents. Results indicate that siblings reported levels of behavioral disturbance which did not significantly differ from those of a contrast group of children referred for psychological services. However, siblings did not differ significantly from a normative group in terms of self-image adjustment. Minimal adjustment differences were found between bereaved siblings and nonbereaved siblings with bereaved siblings reporting poorer adjustment only in the area of body image. Similarly, no significant gender effects on sibling adjustment were found. Results suggest a preponderance of similarity in adjustment for bereaved and nonbereaved siblings. (Author/RJM)

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Family Functioning and Sibling Adjustment Following Treatment of Childhood Cancer

Cindy L. Tucker, Ph.D.
Department of Psychology
Roswell Park Cancer Institute

James C. Hansen, Ph.D.
Department of Counseling and Educational Psychology
SUNY at Buffalo

Michael A. Zevon, Ph.D.
Department of Psychology
Roswell Park Cancer Institute

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For a more complete report, please send requests to:

Cindy L. Tucker, Ph.D.
Department of Behavioral Psychology
The Kennedy Institute
707 N. Broadway
Baltimore, MD 21205

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ABSTRACT

Childhood cancer and its treatment have been identified as significant stressors for individuals and families. The impact of this experience on healthy siblings has not been clearly determined. This study was designed to directly assess siblings regarding their adjustment and their perceptions of their families following the child's treatment. Standardized measures were used to facilitate comparisons. Siblings of children who survived cancer were compared with siblings of children who died of cancer to better understand the complexities of the experience relative to treatment outcome. Subjects were 49 siblings of children treated for cancer and their parents. Twenty-four families were bereaved; the child had successfully completed treatment in 25 families. Siblings ranged in age from 10 to 20 years. Each sibling completed the Youth Self Report, the Offer Self-Image Questionnaire, and the Colorado Self-Report Measure of Family Functioning. Overall, siblings were found to report levels of behavioral disturbance which did not significantly differ from those of a contrast group of children referred for psychological services. However, siblings did not differ significantly from a normative group in terms of self-image adjustment. Minimal adjustment differences were found between bereaved siblings and nonbereaved siblings with bereaved siblings reporting poorer adjustment only in the area of body image. Similarly, no significant gender effects on sibling adjustment were found. Compared with reports of an adolescent normative group, siblings of children treated for cancer reported that their families were less expressive and democratic, and more enmeshed and authoritaritarian. As a group, siblings of children treated for cancer could not be differentiated from the referred contrast group on several dimensions of behavioral disturbance. These results are particularly relevant given that only 14% of these children received any psychological services either during or since the child's diagnosis with cancer. Further, the results indicate a preponderance of similarity in adjustment for bereaved and nonbereaved siblings subsequent to a child's treatment for cancer. Continued study is needed to explicate the complexities of sibling adjustment following childhood cancer.

BACKGROUND

Childhood cancer and its treatment have been identified as significant stressors at both a family and individual level. More recently, researchers have begun to explore the impact of childhood cancer on healthy siblings, both in families where the patient has died and in families where the patient has been successfully treated (Cairns, Clark, Smith, & Lansky, 1979; Horwitz & Kazak, 1990; Iles, 1979; Martinson, Davies, & McClowry, 1987; Pettle-Michael & Lansdown, 1986). However, much of this work has relied heavily on anecdotal data or maternal reports of sibling adjustment. Studies assessing siblings directly have tended to use unstandardized interviews or instruments, rendering results and their significance difficult to interpret. Overall, agreement on the severity of the impact of childhood cancer on siblings and its long-term effects is lacking. Despite the existing investigations, the factors that contribute to positive adaptation of healthy siblings of children with cancer have yet to be determined.

PURPOSE OF THE STUDY

The purpose of present study was to examine the behavioral and self-image adjustment of healthy siblings of children treated for cancer in relation to perceived family functioning. Further, the study was designed to compare bereaved and nonbereaved siblings of children treated for cancer in terms of adjustment and perceived family functioning to explore the potential differential impact on siblings of cancer treatment outcome.

Siblings' perceptions of adjustment and family functioning were assessed directly in order to eliminate potential parental biases. Consistent with the coping model of Lazarus and Folkman (1984), the child's own perceptions rather than the perceptions of others likely mediate coping responses.

The results reported represent preliminary analyses from a larger study designed to develop a discriminant function analysis for the identification of siblings at risk for maladjustment subsequent to a child's treatment for cancer.

RESEARCH QUESTIONS

1. Do siblings of children treated for cancer differ from standardized norms in terms of behavioral or self-image adjustment, or perceptions of family functioning?

2. Do bereaved and nonbereaved siblings of children treated for cancerdiffer in terms of behavioral or self-image adjustment, or perceptions of family functioning?

3. Do female and male siblings of children treated for cancer differ in terms of behavioral or self-image adjustment, or perceptions of family functioning?

METHOD

PARTICIPANTS

Subjects were 49 siblings of children treated for cancer and their parents. Twenty-four families were bereaved and twenty-five children had successfully completed treatment for cancer. To be eligible, siblings were between ages 10 and 20 years, were born at the time of the child's cancer diagnosis, and were living with their parent(s) at the time of the interview. The child's cancer diagnosis occurred within 10 years of the interview, the cancer treatment lasted at least 6 months, and the time since the child's death or the cessation of treatment was greater than four months. Only data for the sibling closest in age to the child with cancer was analyzed in order to maintain an independent sample. Tables 1-4 present descriptive data for the sample.

Table 1 - **Demographics of the Family Sample**

Variables	Total N = 49	Bereaved n = 24	Nonber'ed n = 25	Signif. Tests
Family Composition				
-intact	39 / 79.6%	18 / 75.0%	21 / 84.0%	ϕ = .1116
-other	10 / 20.3%	6 / 25.0%	4 / 16.0%	p = .435
Race				
-Caucasian	42 / 85.7%	21 / 87.5%	21 / 84.0%	ϕ = .0076
-African-American	3 / 6.1%	2 / 8.3%	1 / 4.0%	p = .957
-Asian-Indian	2 / 4.1%	1 / 4.2%	1 / 4.0%	
-Asian	2 / 4.1%	0	2 / 8.0%	
Relig Affiliation				
-Roman Catholic	28 / 57.1%	14 / 58.3%	14 / 56.0%	ϕ = .1637
-Protestant	14 / 28.6%	7 / 29.2%	7 / 28.0%	p = .726
-none	4 / 8.2%	1 / 4.2%	3 / 12.0%	
-Hindu	2 / 4.1%	1 / 4.2%	1 / 4.0%	
-Jewish	1 / 2.0%	1 / 4.2%	0	
SES (Hollingshead)				
-class I/low	2 / 4.1%	2 / 8.3%	0	ϕ = .3144
-class II	3 / 6.1%	2 / 8.3%	1 / 4.0%	p = .304
-class III	12 / 24.5%	5 / 20.8%	7 / 28.0%	
-class IV	15 / 30.6%	5 / 20.8%	10 / 40.0%	
-class V	17 / 34.7%	10 / 41.7%	7 / 28.0%	
Number of Children				
Mean:	3.43	3.71	3.16	t = -1.33
SD:	1.46	1.68	1.18	df = 47
Range:	2-8	2-8	2-6	p = .191

Table 2 - **Demographics of the Sibling Sample**

Variables	Total N = 49	Bereaved n = 24	Nonber'ed n = 25	Signif. Tests
Gender				
-female	21 / 42.9%	12 / 50%	9 / 36.0%	ϕ = .1414
-male	28 / 57.1%	12 / 50%	16 / 64.0%	p = .322
Age at diagnosis/mo				
Mean:	98.31	93.48	102.96	t = 0.84
SD:	39.30	39.19	39.63	df = 47
Range:	7-182	7-182	15-178	p = .403
Age at interview/mo				
Mean:	179.88	186.59	173.44	t = 1.21
SD:	38.13	40.33	35.51	df = 47
Range:	120-241	120-241	122-238	p = .227

Table 3 - **Demographics for Sample of Children Treated for Cancer.**

Variables	Total N = 49	Deceased n = 24	Survivors n = 25	Signif. Tests
Gender				
-female	20 / 40.8%	6 / 25.0%	14 / 56.0%	ϕ = .3153
-male	29 / 59.2%	18 / 75.0%	11 / 44.0%	p = .027*
Age-diagnosis/mo				
Mean:	72.31	89.79	55.52	t = -2.35
SD:	52.91	61.55	37.01	df = 37.41
Range:	1-215	13-215	1-154	p = .024*

Table 4 - **Treatment Demographics for Children Treated for Cancer.**

Variables	Total N = 49	Deceased n = 24	Survivors n = 25	Signif. Tests
Diagnosis				
-leukemia	21 / 42.9%	6 / 25.0%	15 / 60.0%	ϕ = .3536
-NHL	7 / 14.3%	4 / 16.7%	3 / 12.0%	p = .013*
-brain tumor	5 / 10.2%	4 / 16.7%	1 / 4.0%	
-Wilm's tumor	4 / 8.2%	1 / 4.2%	3 / 12.0%	
-bone tumor	3 / 6.1%	2 / 8.3%	1 / 4.0%	
-neuroblastoma	2 / 4.1%	1 / 4.2%	1 / 4.0%	
-other	7 / 14.3%	6 / 25.1%	1 / 4.0%	
Duration of Treatment/mo				
Mean:	25.65	23.42	27.80	t = -0.97
SD:	15.79	18.13	13.18	df = 47
Range:	6-64	6-64	6-49	p = .337
Months since diagnosis				
Mean:	79.14	88.46	70.20	t = 2.66
SD:	25.45	23.95	24.00	df = 47
Range:	20-120	42-120	20-120	p = .011*
Months since treatment ended				
Mean:	52.69	65.17	40.72	t = 3.57
SD:	26.74	27.07	20.55	df = 47
Range:	5-115	5-115	5-82	p=.001***
Months since death	NA		NA	NA
Mean:		67.50		
SD:		25.68		
Range:		21-113		

MEASURES

Siblings were given the following measures:

YSR - Youth Self-Report, (Achenbach, 1991). A parallel instrument to the Child Behavior Checklist, this 112-item multidimensional standardized measure is designed to assess children's perceptions of their behaviors. Higher scores indicate greater levels of behavioral disturbance. The *YSR* includes 3 summary scales and 9 subscales that were utilized with the present sample. The summary scales include:

-Total Behavior Problems (TBP)
-Internalizing (INT)
-Externalizing (EXT).

The subscales include:

-Withdrawn (W)
-Somatic Complaints (SC)
-Anxious/Depressed (AD)
-Social Problems (SOC)
-Thought Problems (THG)
-Attention Problems (ATT)
-Delinquent Behavior (DEL)
-Aggressive Behavior (AGG).

OSIQ - Offer Self-Image Questionnaire, (Offer, Ostrov, Howard, & Dolan, 1989). The *OSIQ* is a widely-used multidimensional self-report measure of adolescent adjustment and well-being. Comprised of 130 items, the *OSIQ* includes 12 subscales and 1 overall adjustment summary scale. Higher scores indicate greater levels of adjustment. The summary scale was labeled:

-OSIQ Total (OSIQ-TOT).

Nine of the twelve subscales were of interest with this sample:

-Impulse Control (IMP)
-Emotional Tone (ET)
-Body Image (BI)
-Social Relationships (SOC)
-Morals (MOR).
-Mastery (MAS)
-Vocational/Educational Goals (VOC)
-Emotional Health (EH)
-Superior Adjustment (SUP)

CSMFF - Colorado Self Report of Family Functioning, Bloom & Naar, 1991). The *CSMFF* is a psychometrically improved measure of family assessment which resulted from a series of factor analyses with 4 existing family scales. It is a 60-item multidimensional, self-report measure of family functioning with 12 subscales. Higher scores indicate a greater level of the characteristic indicated by the subscale label. The subscales include:

-Cohesion (COH)
-Expressiveness (EXP)
-Conflict (CON)
-Organization (ORG)
-Family Sociability (SOC)
-Enmeshment (ENM)
-Family Idealization (IDE)
-Disengagement (DIS)
-Democratic Family Style (DEM)
-Permissive Family Style (PER)
-Authoritarian Family Style (AUT)
-External Locus of Control (LOC).

PROCEDURES

Subject Identification

The mailing list of a local parent fund-raising group was utilized to contact potential subject families. Active group participation was not a prerequisite for inclusion on the mailing list, thereby decreasing concerns of self-selection.

Data Collection

Assessment interviews were conducted by the investigator in the families' homes. Informed consent was obtained from each participant. A semi-structured interview with parents was used to collect demographic and treatment data. Siblings next completed the self-report measures. Debriefing and emotional reactions were assessed and referrals to counseling services were provided.

ANALYSES

t-tests comparing siblings of children treated for cancer with standardized norms for *YSR*, *OSIQ*, and *CSMFF* were planned. The independent variable was *group* membership (siblings vs. normative group), with dependent variables of (a) the summary and subscales of *the YSR*, (b) the summary and subscales of the *OSIQ*, and (c) the subscales of the *CSMFF*.

Two-way MANOVAs (2 x 2 design) were used to compare the degree of behavioral and self-image adjustment among bereaved and nonbereaved female and male siblings. A covariate (*time since diagnosis*) was first entered given that bereaved and nonbereaved samples differed significantly on this variable. The factors were *status* (bereaved vs. nonbereaved) and *gender*. The multivariate dependent variables included (a) the subscales of the *YSR*, (b) the subscales of the *OSIQ*,and (c) the subscales of the *CSMFF*.

The .05 probability level was adopted for reporting significance.

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RESULTS

t-tests comparing siblings with standardized norms:

Overall, siblings of children treated for cancer reported levels of behavioral disturbance which were significantly higher than those reported for a standardized normative group, but which did not differ significantly from those reported for a group of children referred for psychological services (Figures 1 and 2).

Siblings of children treated for cancer reported levels of self-image adjustment which did not differ significantly from those reported for a standardized normative group except in one area. Female siblings reported poorer levels of body image adjustment than did the female normative group (Figures 3 and 4).

Siblings of children treated for cancer reported significantly lower levels of family expressiveness and democratic style, and significantly higher levels of enmeshment and authoritarian style than those reported for a standardized normative group (Figure 5).

MANOVA comparing siblings' behavioral adjustment:

No significant effect of *time since diagnosis* was found. No significant main effects for *status* or *gender* were found. No significant interaction effect between *status* and *gender* was found (Table 5).

MANOVA comparing siblings' self-image adjustment:

No significant effect of *time since diagnosis* was found. A significant main effect for *status* was found with bereaved siblings reporting poorer body image adjustment than did nonbereaved siblings. No significant main effect for *gender* was found. No significant interaction effect between *status* and *gender* was found (Table 6).

MANOVA comparing siblings' perceptions of family functioning:

No significant effect of *time since diagnosis* was found. No significant main effects for *status* or *gender* were found. No significant interaction effect between *status* and *gender* was found (Table 7).

Figure 1
YSR Mean T-Scores of Female Siblings Compared with Female Normative Groups

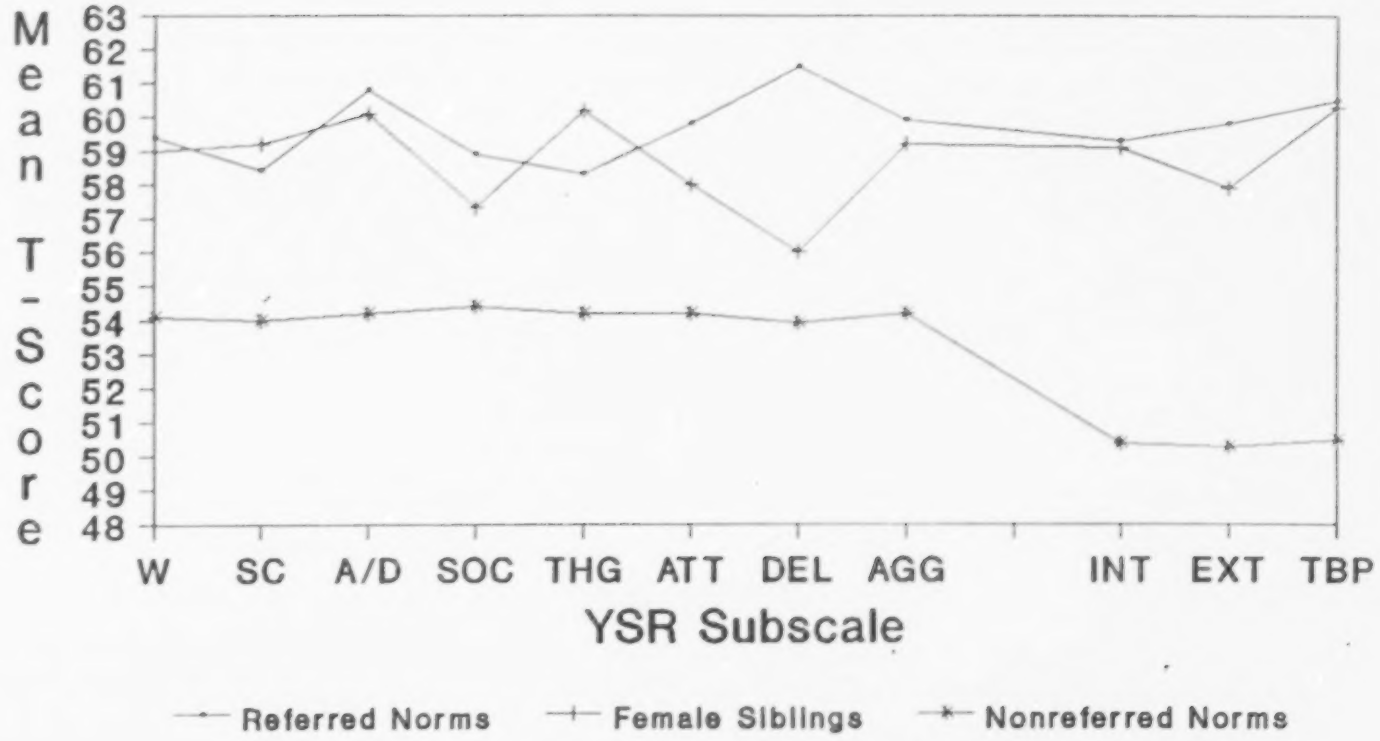

Figure 2
YSR Mean T-Scores of Male Siblings Compared with Male Normative Groups

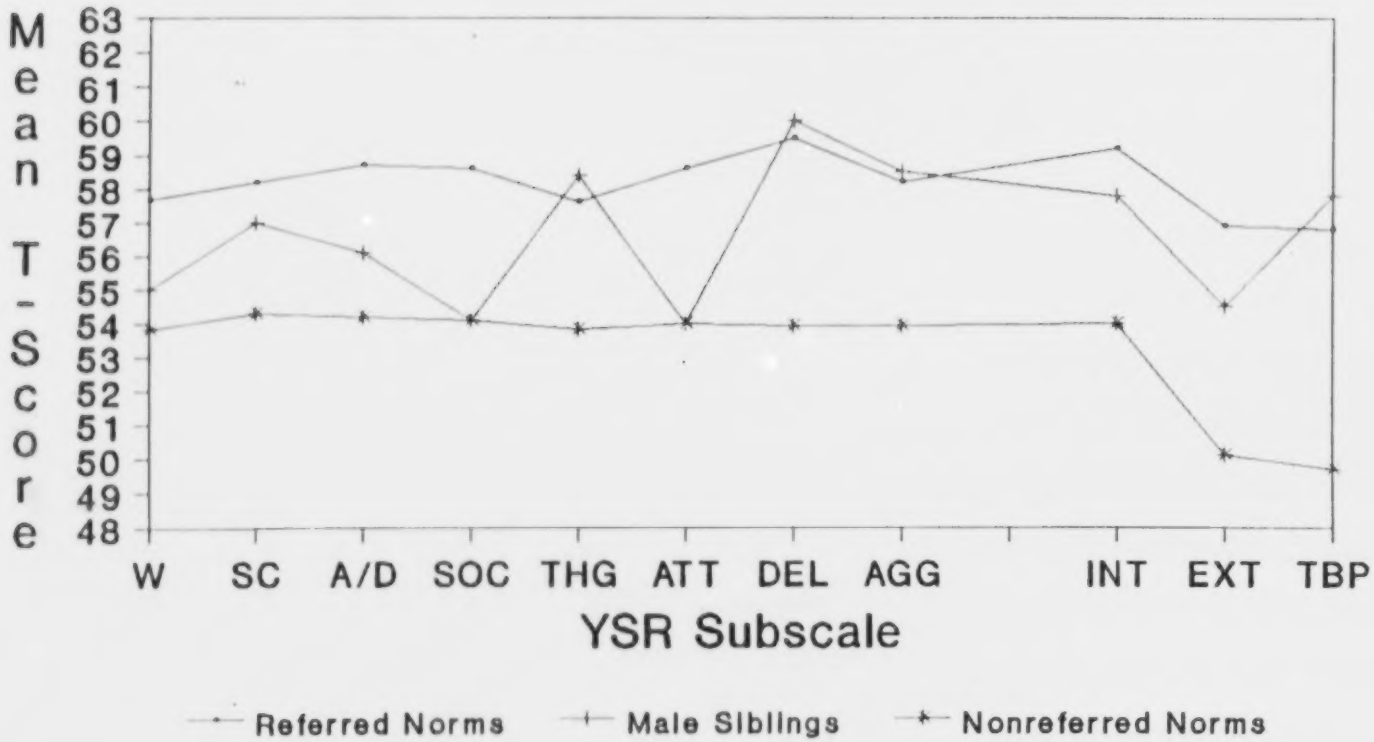

Figure 3
OSIQ Mean Scores of Female Siblings Compared with Younger Female Norm Group

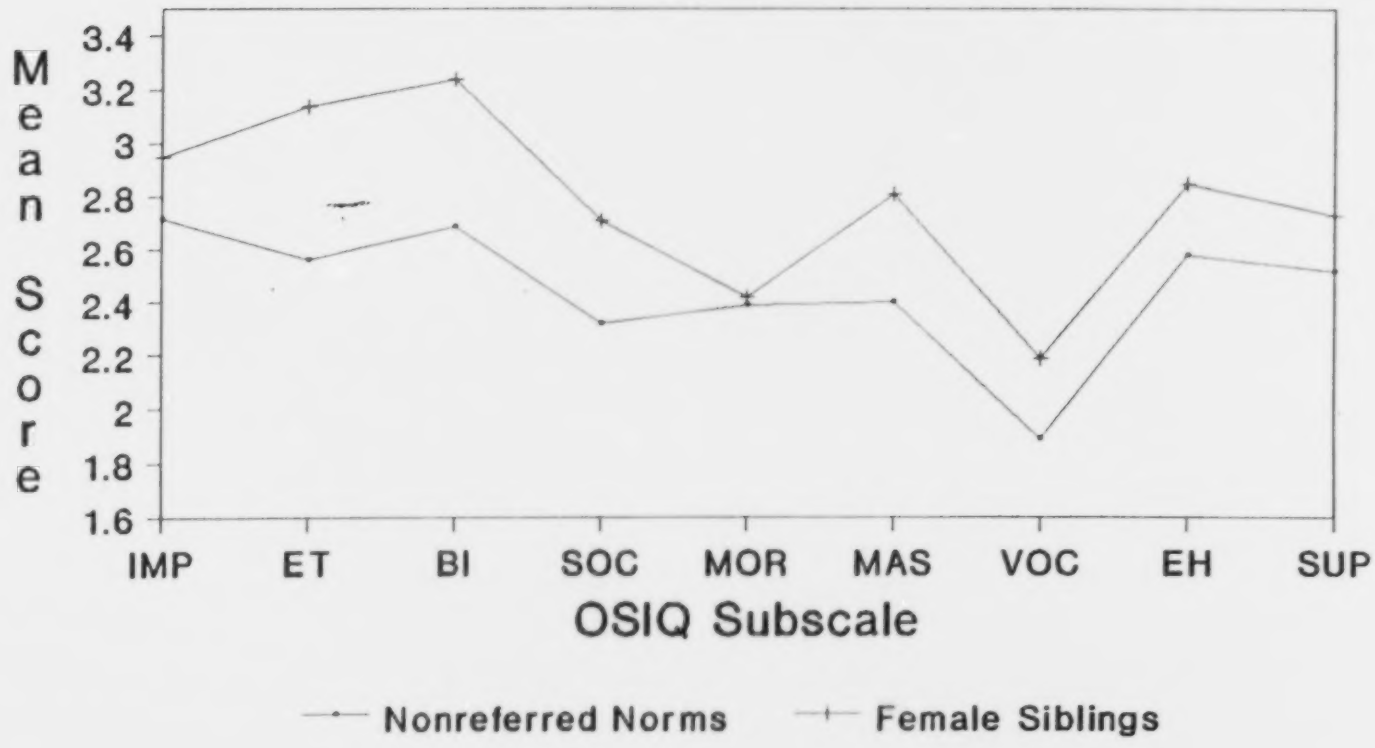

Figure 4
OSIQ Mean Scores of Male Siblings Compared with Younger Male Norm Group

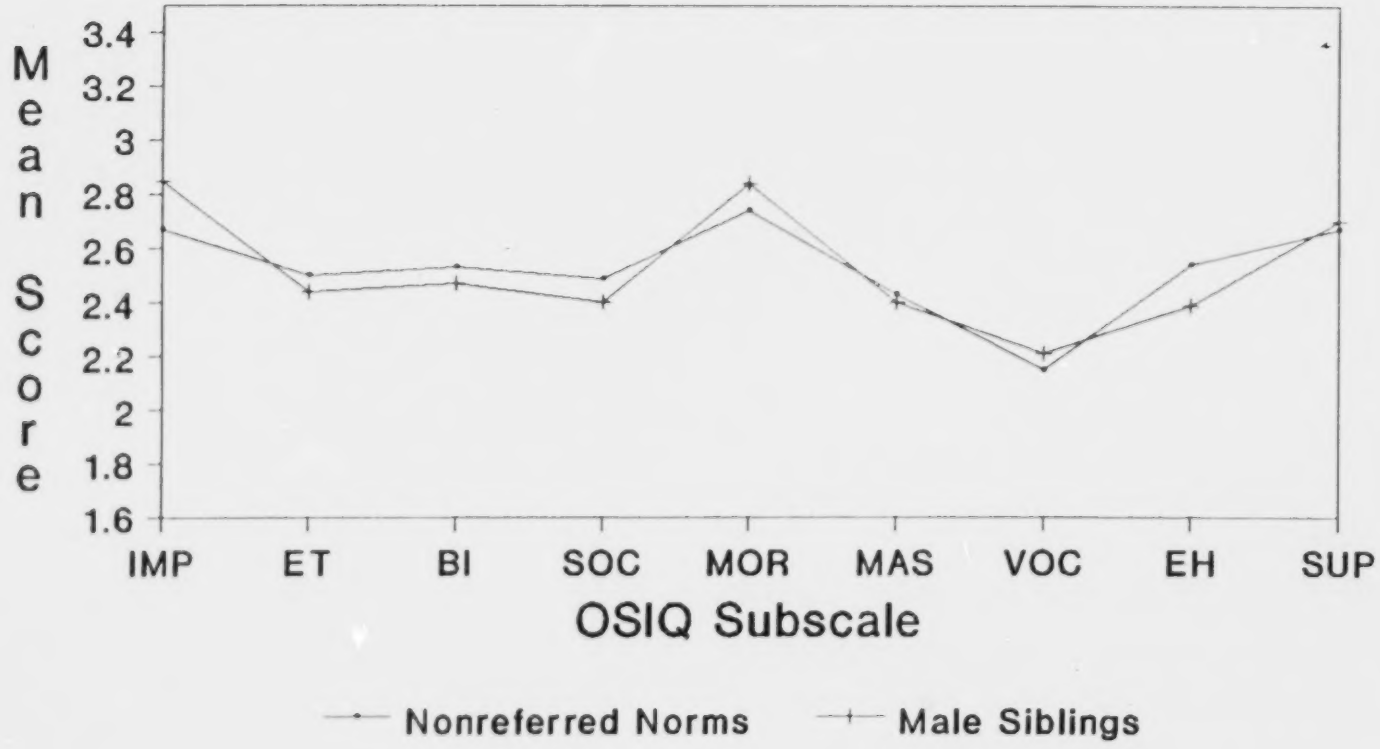

Figure 5
CSMFF Mean Scores of Siblings Compared with High School Student Normative Group

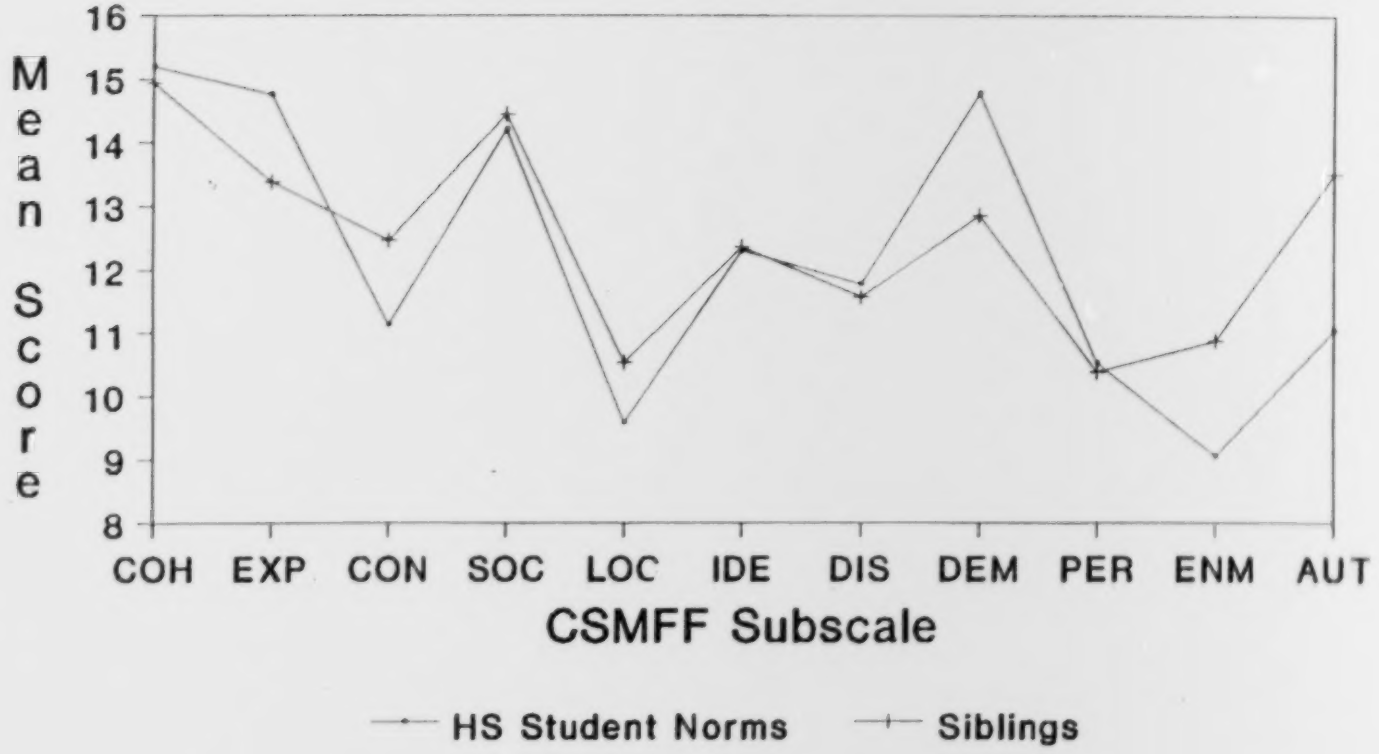

Table 5 - **YSR Subscale Scores of Siblings of Children Treated for Cancer by Status and Gender**

MANOVAs

Covariate - *time since diagnosis*

Wilk's λ	Approximate *F*	df	*p*
0.7531	1.2703	8,31	.294

Factor-*status*

Wilk's λ	Approximate *F*	df	*p*
0.8217	0.8412	8,31	.574

Factor-*gender*

Wilk's λ	Approximate *F*	df	*p*
0.6871	1.7650	8,31	.123

Factor-*status X gender*

Wilk's λ	Approximate *F*	df	*p*
0.9194	0.3397	8,31	.943

Table 6 - **OSIQ Subscale Scores of Siblings of Children Treated for Cancer by Status and Gender**

MANOVAs

Covariate - *time since diagnosis*

Wilk's λ	Approximate *F*	df	*p*
0.7372	1.3469	9,34	.250

Factor-*status*

Wilk's λ	Approximate *F*	df	*p*
0.6030	2.4871	9,34	.026 *

Univariate ANOVA / *Roy-Bargmann Stepdown F-Tests*

Dependent Variables-*OSIQ Subscales*

Subscale	Source	SS	MS	df	Stepdown *F*	*p*
Impulse Control	between within	311.95 11902.32	311.95 283.39	1 42	1.1008	.300
Emotional Tone	between within	87.03 12600.92	2.89 193.70	1 41	0.0149	.903
Body Image	between within	594.37 10184.04	938.97 139.05	1 40	6.7528	.013*
Social Rel'ships	between within	4.22 11787.88	10.72 129.21	1 39	0.0830	.775
Morals	between within	915.66 12420.96	87.64 232.76	1 39	0.3765	.543
Mastery	between within	297.13 11578.91	346.89 91.88	1 36	3.7756	.060
Voc/Educ Goals	between within	21.34 12968.43	490.55 159.66	1 37	3.0724	.088
Emotional Health	between within	65.94 14833.29	78.65 146.57	1 35	0.5366	.469
Superior Adjustment	between within	279.53 10857.43	569.64 135.12	1 34	4.2160	.048*

Table 6 - Continued

MANOVAs

Factor-*gender*

Wilk's λ	Approximate *F*	df	*p*
0.7417	1.3158	9,34	.265

Factor-*status X gender*

Wilk's λ	Approximate *F*	df	*p*
0.7276	1.4141	9,34	.221

Table 7 - **CSMFF Scale Scores of Siblings of Children Treated for Cancer by Status and Gender**

MANOVAs

Covariate - *time since diagnosis*

Wilks λ	Approximate *F*	df	*p*
0.7148	1.0972	12,33	.394

Factor-*status*

Wilk's λ	Approximate *F*	df	*p*
0.7979	0.6967	12,33	.743

Factor-*gender*

Wilk's λ	Approximate *F*	df	*p*
0.7948	0.7098	12,33	.731

Factor-*status X gender*

Wilk's λ	Approximate *F*	df	*p*
0.7811	0.7707	12,33	.675

CONCLUSIONS

As a group, siblings of children treated for cancer tended to report levels of behavioral disturbance that fell between those reported for a standardized normative group and those reported for a group of children referred for psychological services. These results differ somewhat from those typically reported for this population. Obtaining behavioral reports directly from the siblings (rather than parents or teachers) likely accounts for the observed differences.

The siblings could not be differentiated from the referred contrast group on several dimensions of behavior including somatization, anxiety and depression, thought problems, and aggressive behaviors. These results are particularly relevant given that only 14% of these children had received any psychological services during or since the diagnosis of their sibling with cancer.

The results did not support the hypothesized differences in self-image adjustment between siblings of children treated for cancer and a normative group of adolescents. It appears that these two theoretical realms of sibling adjustment are distinct and are differentially impacted by the sibling's cancer experience.

While healthy self-image adjustment appears to be intact for the siblings in this sample, the substantial degree of behavioral disturbance endorsed indicates that these children are experiencing distress following the cancer treatment which is being manifested through their behavior and mood states. For these siblings, the experience of having a sister or brother treated for cancer appears to have resulted in a more reactive type of distress of behavioral vulnerability, rather than self-concept disturbances or disorders.

Siblings of children treated for cancer reported higher levels of enmeshment and authoritarian family style and lower levels of expressiveness and democratic family style than a comparable normative sample. There was a trend for siblings to report higher levels of conflict and external locus of control as well. Such families would tend to discourage direct expression of feelings and opinions, and participation in decision-making. They would tend to demonstrate diffuse boundaries, difficulty in resolving conflict, and a sense of powerlessness.

It should not be assumed that the pattern of family functioning reported by this sample of siblings is necessarily dysfunctional for families of children treated for cancer. Kazak (1992, 1989) indicated that such patterns may actually be normative for families as they face the uncontrollable nature and intense demands of the disease process. Accordingly, a more relevant issue than normal vs. abnormal response would be the consequences of various family functioning patterns upon long-term sibling adjustment. Further study is needed.

The length of time since the child's diagnosis was found not to covary with siblings' scores on the adjustment and family functioning measures. Similarly, no significant differences were found in adjustment or perceived family functioning between female and male siblings. In terms of behavioral adjustment and perceptions of family functioning, no significant differences were found between bereaved and nonbereaved siblings. Only in the realm of body image adjustment did bereaved siblings report poorer adjustment than did nonbereaved siblings.

Overall, these results may challenge the expectations that bereaved siblings and their families would be uniformly less well adjusted than nonbereaved siblings and families. Further, in this cross-sectional sample, distress was not reported to diminish over time. It is unclear whether the degree of adjustment and the family functioning patterns predated the child's cancer diagnosis, representing enduring sibling and family traits or, conversely, if the adjustment and patterns observed developed in response to the child's illness, but have not been modified subsequent to cessation of the child's treatment.

The underlying mechanism by which time since diagnosis and the child's treatment outcome impact on sisters and brothers is unclear. In this sample of both bereaved and nonbereaved siblings, significant behavioral disturbances and altered family functioning patterns remained present two to ten years after the child's cancer diagnosis. This finding is important to our understanding of sibling adaptation given the expectations for resolution of distress often encountered by family members of children treated for cancer. Further, while quantitative differences in distress were not found between bereaved and nonbereaved siblings, future investigations are needed to explore the probable qualitative differences associated with treatment outcome.

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